

FTR

NB 5432

February 17, 2013

To Whom It May Concern,

It all began for us almost eight years ago. Our son Maddox was 16 months old when we finally found out why he was having failure to thrive. At this time he was 5lbs below the 5th percentile for weight and would not eat. After having an endoscopy and colonoscopy (yes that's right, a 16 moth old going through this), we found out that he has Eosinophilic esophagitis (EE). We took him off all milk and soy proteins immediately. He was given a couple of months to see if he could/would start eating more on his own, after being off the milk and soy, and unfortunately he didn't. His weight was so low that if we didn't start getting the nutrition in him, it would have started to affect his brain and bones. We got a feeding tube in right away at that point, and he was put on a hypoallergenic formula (Neocate Jr.) through the feeding tube. This was his main source of nutrition for many years. Just the formula, was a little over \$900.00 a month, and that doesn't include the cost of his button, feeding pump, bags, syringes etc. Even with insurance it is still a big chunk of money, I have no idea what we would have done without it being covered. We know that getting the feeding tube when he did has saved his life. He is 9 years old now and still needs the feeding tube to supplement his daily intake. We have tried and tried to get him to orally consume enough food on his own, and still, he physically can't do it. He doesn't need it as often as he has in the past, but there have been a couple of times we have stopped the tube feeds to see if he can do it on his own....unfortunately he loses weight when we try this and he cannot afford to lose any weight. We pray for the day that he will not have to rely on his tube feeds (to get him his neocate Jr. he needs for proper nutrition), but at this point, it's still something he needs, to survive and thrive. It scares me that he is so close to the age cut off, when the insurance companies will stop covering it. We NEED this to be changed, there should be no age cut off. Trust me, if we could get our children off of needing these high priced hypoallergenic formulas, we SO would. We have needed it for our son for 8 years now, and it has saved his life. He is a fun loving, super-smart, caring, lego loving little guy and we want him to continue to thrive. We have so many worries already with all the medical stuff involved with his disease, please

don't make us worry that coverage will end once our children reach the still very young age of 12 years. If children still need the hypoallergenic formulas to survive at that age, then it should be covered, they deserve that.

Please think long and hard about the decision you make. Think about if your child was in this situation, how they could only survive with this medical formula. It is so hard to understand the importance of it and the medically necessary need for this formula, but try, please try.

Thank you for listening to our story (summed up) of our amazing son, Maddox.

Sherry and Joey Bruening

